

Guide to Chapter 1

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CHAPTER 1

Medicaid Coverage of Home and Community Services: Overview¹

Long-term care includes a broad range of health and health-related services, personal care, social and supportive services, and individual supports. This chapter recounts the legislative, regulatory, and policy history of Medicaid coverage of long-term care services. Both institutional and home and community long-term care services are covered, with the latter described in greater detail. (Medicaid's coverage of primary and acute care is not included in the discussion.)

Introduction

Medicaid is an entitlement program, which is designed to help states meet the costs of necessary health care for low-income and medically needy populations. States qualify to receive Federal matching funds to help finance these costs by filing a state Medicaid plan document with the Federal Health Care Financing Administration (HCFA).² States have substantial flexibility to design their programs within certain broad Federal requirements related to eligibility, services, program administration, and provider compensation.

Program Evolution and Current Spending Allocations

From its beginnings as a health care financing program primarily for welfare recipients, Medicaid has been amended and expanded in a patchwork fashion to cover a range of populations. Initially, Medicaid was the medical care extension of Federally funded programs providing cash assistance for the poor, with an emphasis on dependent children and their mothers, elderly persons, and persons with disabilities. Legislation in the 1980s extended Medicaid coverage to an expanded group of low-income pregnant women and poor children, and to some low-income Medicare beneficiaries who were not eligible for cash assistance.

When first enacted, Medicaid's main purpose was to cover primary and acute health care services, such as doctor visits and hospital stays. Mandatory coverage for long-term care was limited to skilled nursing facility (SNF) services for people age 21 and older. States were given the option to cover home health services and private duty nursing services. In response to the high costs of nursing facility care, combined with criticism of Medicaid's institutional bias, states and the Federal government began to

look for ways to provide long-term care services in less restrictive, more cost-effective ways. In 1970, home health services for those entitled to nursing home care became mandatory. Since 1970, Medicaid has evolved into a program that allows states considerable flexibility to cover virtually all long-term care services that people with disabilities need to live independently in home and community settings.

The Federal Medicaid statute requires states to specify the amount, duration, and scope of each service they provide, which must be sufficient to reasonably achieve its purposes. States may not place limits on services or arbitrarily deny or reduce coverage of required services solely because of diagnosis, type of illness, or condition. Generally, a state plan must be in effect throughout an entire state (i.e., amount, duration, and scope of coverage must be the same statewide). There are certain exceptions to these rules. Two major ones: (a) states operating home and community based services (HCBS) waivers need not offer all services covered under the waiver to all beneficiaries in the state; and (b) targeted case management services offered as an optional benefit under the state plan are not subject to the statewideness rule.³

In 1999, every state was providing home and community services under one or more of the available options, and Medicaid had become the nation's major public financing program for long-term care services for low-income persons of all ages with all types of physical and mental disabilities. Data since 1988 show how Medicaid long-term care service spending has been changing.

In 1988, Medicaid spending for all long-term services totaled \$23 billion.⁴ Nearly 90 percent of those dollars paid for institutional services in nursing facilities and intermediate care facilities for persons with mental retardation (ICFs/MR); only 10 percent went for home and community services. Over the next eleven years, Medicaid spending for all long-term care services grew by 9.8 percent per year, reaching \$63.9 billion by 1999. Spending for institutional services increased more slowly (at 7.6 percent per year). Spending for home and community services grew at the rate of 20 percent per

year. From a low level of expenditures, home and community spending reached \$17.9 billion in 1999.⁵

HCBS waiver programs accounted for the majority of this growth. In 1999, HCB waiver services accounted for 16.6 percent of all Medicaid long-term care services, compared with 9.4 percent in 1994 and only 4.4 percent in 1990. In 1996, expenditures for HCB waiver services surpassed spending for services provided under the home health benefit and the personal care option combined for the first time. In the eleven years from 1988 to 1999, the proportion of total Medicaid spending that went to all home and community services (waiver, personal care, targeted case management, and home health combined) grew from 10 to 28 percent.⁶ Following the Supreme Court's 1999 *Olmstead* decision, a state may decide to make increased use of the Medicaid program to increase both the amount and share of its resources going to home and community services.

Expansion of home and community services relative to institutional services has been particularly pronounced for individuals with mental retardation and other developmental disabilities. In 1990, 144,000 such individuals were served in ICFs/MR, compared with 45,000 receiving HCB waiver services. By 1999, the number served in ICFs/MR had dropped to 118,000 while the number participating in HCBS waiver programs had increased to almost 262,000.⁷

It should be noted, however, that the share of Medicaid long-term care spending going to home and community services in most states is much lower than the nationwide figure of 28 percent would lead one to expect. In 1997, for example, that share was less than 8 percent in half the states. In the same year, however, five states spent more than 20 percent of their Medicaid long-term care resources on home and community services, with Oregon and New York heading the list (at 40 to 50 percent). The median annual per capita Medicaid expenditure on home and community services has also increased (rising from \$310 to \$522 between 1992 and 1997).⁸ This overall figure again masks considerable state variation—from \$1180 per person age 65 or over in New York

down to \$29 in Mississippi.⁹

Major Contours of the Medicaid Program's Home and Community Service Provisions

The remainder of this chapter presents a brief overview of the Medicaid law, regulations, and policy that give states the flexibility to create comprehensive home and community service systems for persons of all ages with all types of physical and mental disabilities. To provide context for the discussion, Table 1-1 lists the major relevant provisions of Medicaid law. This chronological summary illustrates the progressive expansion of Medicaid long-term care services away from a primary focus on institutional care. (Chapters 4 and 5 discuss service options and factors to consider when choosing among them.)

Home Health Services

There has been some misunderstanding about the coverage criterion for home health services because it is linked to the coverage criterion for nursing homes. States are mandated to cover nursing home care for categorically eligible persons age 21 and older. This mandate *entitles* persons age 21 and older to nursing facility care. States have the option to cover nursing home care for other Medicaid beneficiaries as well—e.g., persons under age 21 and the medically needy. In states choosing this option, the medically needy and persons under age 21 would also be *entitled* to nursing home care. However, being *entitled* to nursing home care does not mean that one is *eligible* for nursing home care. In order to receive Medicaid covered nursing home care, entitled persons must also meet nursing home *eligibility* criteria (called level-of-care criteria).

Since 1970, home health services have been mandatory for persons entitled to nursing facility care.¹⁰ Confusion about eligibility for home health services has arisen because the term *entitled* to nursing facility care has sometimes been erroneously interpreted to mean that people must be

eligible for nursing facility care—i.e., that they must meet a state's nursing facility level-of-care criteria—in order to receive home health benefits. This erroneous interpretation has persisted notwithstanding its conflict with home health regulations prohibiting a state from conditioning eligibility for home health services on the *need for* or discharge from institutional care.¹¹ The Medicaid Assistance Manual further clarifies that states may not limit home health services to individuals who require a skilled level of health care as defined by Medicare (i.e., needing skilled nursing or therapy services).¹² (See Chapter 3 for additional information on the home health benefit.)

Federal regulations require that home health services include nursing, home health aides, medical supplies, medical equipment, and appliances suitable for use in the home. States have the option of providing additional therapeutic services under home health—including physical therapy, occupational therapy, and speech pathology and audiology services.¹³ States may establish reasonable standards for determining the extent of such coverage based on such criteria as medical necessity or utilization control.¹⁴ In doing so, as noted, a state must ensure that the amount, duration, and scope of coverage are reasonably sufficient to achieve the purpose of the service.¹⁵

In 1998, following the ruling of the U.S. Court of Appeals for the Second Circuit in *DeSario v. Thomas*, HCFA sent a letter to state Medicaid Directors clarifying that states may develop a list of pre-approved items of medical equipment as an administrative convenience but must provide a reasonable and meaningful procedure for requesting items that do not appear on such a list.¹⁶ (See Appendix II for the complete text of the HCFA letter.) All home health services must be medically necessary and authorized on a physician's orders as part of a written plan of care.

Home health services are defined in Federal regulation as services provided at an individual's place of residence. In 1997, however, the Federal Court of Appeals for the Second Circuit ruled that home health nursing services may be provided outside the home, as long as they do not exceed the hours of nursing care that would have been provided in the home.¹⁷ The states covered

Table 1-1. Medicaid's Legislative Provisions Regarding Long-Term Care Services

1965	Establishment of Medicaid ¹⁸ — Mandatory coverage of SNFs — Optional coverage of home health services and rehabilitation services.
1967	Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) mandate for children under 21. ¹⁹ States given the option to provide services under EPSDT that were not covered by their state plans.
1970	Mandatory coverage of home health services for those entitled to skilled nursing facility services. ²⁰
1971	Optional coverage of intermediate care facilities (ICFs) and ICFs/MR. ²¹
1972	Optional coverage of children under 21 in psychiatric hospitals. (This institutional coverage provides the "institutional alternative" for HCBS waiver services for this group.) ²²
1973	Option to allow people receiving supplemental security income (SSI) to return to work and maintain their Medicaid benefits. ²³
1981	Establishment of home and community based services (HCBS) waiver authority. ²⁴
1982	Option to allow states to extend Medicaid coverage to certain children with disabilities who live at home but who, until this 1982 provision, were eligible for Medicaid only if they were in a hospital, nursing facility, or ICF/MR. Also known as the Katie Beckett or TEFRA Provision. ²⁵
1986	Option to cover targeted case management. States are allowed to cover such services without regard to the statewide and comparability requirements. ²⁶ Option to offer supported employment services through HCBS waiver programs to individuals who had been institutionalized some time prior to entering the HCBS waiver program. ²⁷
1988	Establishment of special financial eligibility rules for institutionalized persons whose spouse remains in the community, to prevent spousal impoverishment. ²⁸
1989	EPSDT mandate amended to require states to cover any service a child needs, even if it is not covered under the state plan. ²⁹
1993	Removal of requirements for physician authorization and nurse supervision for personal care service provided under the state plan. States were given explicit authorization to provide personal care service outside the individual's home. ³⁰
1997	Removal, under the Balanced Budget Act of 1997, of the "prior institutionalization" test as a requirement for receiving supported employment services through an HCBS waiver program. Addition of first opportunity for states to create a Medicaid "buy-in" for people with disabilities.
1999	Additional options under the Ticket to Work and Work Incentives Act for states to create a buy-in program for people with disabilities and to remove employment barriers. ³¹

by this ruling are New York, Connecticut, and Vermont. (See Chapter 3 for additional information on this ruling.)

EPSDT

The Federally mandated EPSDT program for children from birth to 21 years entitles Medicaid eligible children to services found necessary to diagnose, treat, or ameliorate a defect, physical or

mental illness, or a condition identified by an EPSDT screen. The original 1967 legislation gave states the option to cover treatment services not covered under the state's Medicaid plan. In 1989, Congress strengthened the mandate by requiring states to cover all treatment services, *regardless of whether or not those services are covered in the state's Medicaid plan*.³²

As a result, the EPSDT component now covers the broadest possible array of Medicaid services, including personal care and other services provid-

ed in the home. For example, Wisconsin covers up to eight weeks of intensive in-home services for children with serious emotional disturbances, including parental skill training in behavior management techniques.

Optional Institutional Services

Options for covering institutional services assumed greater importance after 1981, when the waiver authority was created. This was because HCB waiver services can be provided only insofar as they provide an alternative to institutional care. *If a state is not covering a particular type of institutional service, it will not be able to offer that type of service in the community under an HCBS waiver program.*

The 1971 addition of services provided by ICFs and ICFs/MR as an optional benefit moved the Medicaid program into financing additional nursing home care. Adding optional institutional coverage of ICFs/MR made Federal matching funds available to help finance home and community services for persons with mental retardation (which had previously been supportable only with state funds), thus providing the institutional alternative for MR/DD waivers. Likewise, optional coverage of ICFs made Federal matching funds available for community coverage of a non-skilled level of care through aged/disabled waivers.³³

Optional Home and Community Services

When Medicaid was enacted, states were given the option of covering a wide range of services, several of which can be used in home and community settings. They include rehabilitation services, private duty nursing, physical and occupational therapy, and transportation services. In 2000, every state provided at least one optional service.

The rehabilitation option, in particular, offers states the means to provide a range of supportive services to people in home and community settings. Medicaid defines rehabilitation services as any medical or remedial services recommended by a physician for maximum reduction of physical or mental disability and restoration of a recipient

to his or her best possible functional level.³⁴ Rehabilitation services can be provided to people with either physical or mental disabilities.

The rehabilitation service option is a very flexible benefit, because services may be furnished either in the person's residence or elsewhere in the community. Many states cover psychosocial rehabilitation services, which—when combined with personal care and targeted case management services—can meet a wide range of service and support needs for persons who have a mental illness. In 1996, 31 states used the rehabilitation option for both categorically needy and medically needy populations; 13 additional states used it just for the categorically needy; and 9 states had Medicaid demonstration programs for rehabilitation services.³⁵

The rehabilitation option is not generally used to furnish long-term services and supports to individuals with disabilities other than mental illness. During the 1970s and 1980s, a few states secured HCFA approval to cover daytime services for persons with MR/DD under either the clinic or the rehabilitation option. However, HCFA ultimately ruled that the services being furnished were *habilitative* rather than *rehabilitative* and consequently could not be covered under either option.³⁶ (This issue is discussed in more detail in Chapter 4.)

The main basis for HCFA's ruling was that habilitative services could only be furnished to residents of ICFs/MR under the state Medicaid plan or through an HCBS waiver program for individuals otherwise eligible for ICF/MR services. A few states have maintained their state plan coverage of these services. Other states have terminated those coverages in favor of offering similar services through an HCBS waiver program.³⁷

Personal Care Services

Since the mid-1970s, states have had the option to offer personal care services under the Medicaid state plan, making these services one of the longest standing Medicaid home and community benefits. This option was first established administratively under the Secretary's authority to add coverages over and above those spelled out in Section 1905 of the Social Security Act, if such

services would further the Act's purposes. In 1993, Congress took the formal step of adding personal care to the list of services spelled out in the Medicaid statute.³⁸

When the option for states to offer personal care was created, it had a decidedly medical orientation. The services had to be prescribed by a physician, supervised by a registered nurse, and delivered in accordance with a care plan. Moreover, they could be provided only in the person's place of residence. Generally, the personal care services a state offered were tied mainly to assisting individuals in activities of daily living (ADLs)—bathing, dressing, eating, toileting, and transferring from a bed to a chair. Personal care workers could provide other forms of assistance (e.g., housekeeping and laundry) only on a limited basis and only if they were incidental to delivery of personal care services.

Starting in the late 1980s, some states sought to broaden the scope of personal care services and provide them outside the individual's home in order to enable beneficiaries to participate in community activities. In 1993, Congress not only formally incorporated personal care into Federal Medicaid law but also gave states explicit authorization to provide personal care outside the individual's home.³⁹ Congress went even a step further in 1994, allowing states to: (1) use means other than nurse supervision to oversee provision of personal care services, and (2) establish means other than physician prescription for authorizing such services. In November 1997, HCFA issued new regulations concerning optional Medicaid state plan personal care services to reflect these statutory changes.⁴⁰

In 2000, 27 states covered personal care services under their Medicaid state plans.⁴¹ However, Federal-state Medicaid outlays for these services, which totaled roughly \$3.5 billion in FY1999, have grown at a relatively slow pace during the 1990s.⁴² This slow pace is at least in part because some states are electing to cover personal care services through more flexible and easy to target HCBS waiver programs instead of adding the coverage to their state plan or expanding the state plan coverage they already have in place.

In January 1999, HCFA released a State Medicaid Manual Transmittal that thoroughly revised and updated the Agency's guidelines concerning coverage of personal care services. The new Manual materials made it clear that personal care services may span provision of assistance not only with ADLs but also with Instrumental Activities of Daily Living (IADLs), such as personal hygiene, light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management. HCFA also clarified that all relatives except "legally responsible relatives" (i.e., spouses and parents of minor children) could be paid for providing personal care services to beneficiaries.

The Manual further clarified that, for persons with cognitive impairments, personal care may include "cueing along with supervision to ensure the individual performs the task properly." And it explicitly recognized that provision of such services may be directed by the people receiving them. This consumer direction includes the individuals' supervision and training of their personal care attendants. [For the complete text see Appendix II.] Consumer direction of personal care services has been a feature of many personal assistance programs for many years (both under Medicaid and in programs funded only with state dollars). For example, consumer-direction was built into the Massachusetts Medicaid personal care program from its inception. The HCFA Manual clearly acknowledges and sanctions this model. (See Chapter 7 for in-depth discussion of consumer direction.)

But neither the statutory provisions nor the revised Federal regulations and HCFA State Medicaid Manual guidelines dictate that a state *must* change the scope of its pre-1993 personal care coverage. In order to take advantage of these changes, a state must file an amendment to its state plan. Taken together, therefore, these groundbreaking changes in Federal policy can help pave the way for a state to make its coverage of these services much broader than was the case in the past. But the states must act to bring about these changes in their own personal care programs.

Other State Plan and Optional Services

In addition to services listed under the “long-term services and supports” rubric, many other Medicaid benefits are relevant in meeting the needs of individuals with disabilities and chronic conditions. For example, states can provide powered wheelchairs and other mobility equipment through their coverage of medical equipment and supplies suitable for use in the home.⁴³ State plans also cover many therapeutic services (e.g., occupational and physical therapy) that enable people with disabilities to achieve and maintain optimal functioning. (See Chapter 4 for further discussion.)

Establishment of HCBS Waiver Authority

In 1981, Congress authorized the waiver of certain Federal requirements to enable a state to provide home and community services (other than room and board) to individuals who would otherwise require SNF, ICF, or ICF/MR services reimbursable by Medicaid. The waiver programs are called 1915(c) waivers, named after the section of the Social Security Act that authorized them.⁴⁴

Under 1915(c) waiver authority, states can provide services not usually covered by the Medicaid program, as long as these services are required to keep a person from being institutionalized. Services covered under waiver programs include: case management, homemaker, home health aide, personal care, adult day health, habilitation, respite care, “such other services requested by the state as the Secretary may approve,” and “day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness.”

All but the last were included when the statute was first enacted in 1981. Services for individuals with a chronic mental illness were added in the late 1980s. Neither the statute itself nor HCFA regulations further specify or define the scope of the listed services. However, the law that created the waiver program expressly permits the Secretary to approve services beyond those specifically spelled out in the law, as long as they are necessary to avoid institutionalization and are cost-

effective. In the 19 years of the program’s existence, HCFA has approved a wide variety of additional services.

In the early 1990s, HCFA first issued a standard HCBS waiver application format for states to submit requests to operate an HCBS waiver program. The standard format includes definitions of services states commonly cover in their HCBS waiver programs. The services listed in the standard format appear there because they: (a) are included in the listing contained in the statute, or (b) are additional services frequently offered by states. The standard HCBS waiver application format now contains HCFA-suggested definitions of services states may cover under their HCBS waiver programs. HCFA revises this standard format periodically, occasionally adding new services. (A complete listing of HCFA’s service definitions is in Appendix I.) The services a state may offer are by no means limited to those that appear in the standard format. (See Chapter 4 for a detailed discussion of HCB waiver service coverage possibilities.)

All states have HCBS waiver programs. In June 2000, there were 242 waiver programs approved by HCFA.⁴⁵ States typically operate three or four, but some states offer more. Colorado, for example, operates ten. Federal-state spending for HCB waiver services totaled \$10.6 billion in 1999. Roughly two-thirds of this underwrote HCB waiver services for people with developmental disabilities; the remaining third paid for HCB waiver services for other population groups.⁴⁶

Nationwide, the number of individuals participating in HCBS waiver programs increased from 240,000 in 1992 to an estimated 622,000 in 1998, reflecting an annual rate of increase of 17.2 percent. Individuals with developmental disabilities accounted for 39.7 percent of all waiver participants in 1998, about the same proportion as in 1992. Waiver programs for individuals with other disabilities (e.g., younger persons with non-developmental disabilities and/or persons over age 65 with disabilities) accounted for an estimated 57.1 percent of all participants in 1998. Highly targeted HCBS waiver programs (e.g., programs serving individuals with HIV/AIDS, persons with mental illness, persons who have had a brain injury or another brain disorder, and children with severe

medical disabilities) accounted for the remaining 3.2 percent of program participants.⁴⁷

Average cost of HCB waiver services

In 1998, the cost of HCB waiver services was about \$14,950 per participant. However, there were marked differences in costs among HCBS waiver target populations. The average cost of HCB waiver services for people with developmental disabilities was \$29,353 per participant. In contrast, HCBS waiver programs that serve seniors and/or younger persons with non-developmental disabilities incurred an average cost per participant of \$5,362.⁴⁸ The differences in HCBS waiver costs among target population groups stem from a wide variety of factors. Major factors that affect costs include: (a) differences in the intensity of the services particular target populations require; and (b) the extent to which other state plan services can meet the needs of the target population (and thereby reduce the costs of the additional services that are furnished through HCBS waiver programs). Historically, the costs of supporting individuals with developmental disabilities through HCBS waiver programs have been well above costs of supporting other target populations, because a relatively high percentage of waiver participants with developmental disabilities have been receiving residential rather than in-home services.

The Katie Beckett Provision

The Katie Beckett provision is a statute—the Tax Equity and Fiscal Responsibility Act (TEFRA) 134—added to Medicaid in 1982. Katie Beckett is the name of the child whose parents petitioned the Federal government for her to receive Medicaid services at home instead of in a hospital, and whose plight led the Reagan Administration to urge Congress to enact the provision. TEFRA 134 gives states the option to cover noninstitutionalized children with disabilities. Prior to enactment of this provision, if a child with disabilities lived at home, the parents' income and resources were automatically counted (deemed) as available for medical expenses. However, if the same child was institutionalized for 30 days or more, only the child's own income and resources were counted in the deeming calculation—sub-

stantially increasing the likelihood that a child could qualify for Medicaid. This sharp divergence in methods of counting income often forced families to institutionalize their children simply to get them medical care.

TEFRA 134 amended the Medicaid law to give states the option to waive the deeming of parental income and resources for children under 18 years old who were living at home but would otherwise be eligible for Medicaid-funded institutional care. Not counting parental income enables these children to receive Medicaid services at home or in other community settings. Many states use this option, which requires states to determine that (1) the child requires the level of care provided in an institution; (2) it is appropriate to provide care outside the facility; and (3) the cost of care at home is no more than the cost of institutional care. In states that use this option, parents may choose either institutional or community care for their Medicaid eligible children.

Targeted Case Management

Until 1986, the only practical avenue available for a state to secure Medicaid funding for freestanding case management services (i.e., case management services not delivered as part of some other service or conducted in conjunction with the state's operation of its Medicaid program) was through an HCBS waiver program. Coverage of case management services in HCBS waiver programs was nearly universal at that time.

In 1986, Congress created the option for states to cover what were termed "targeted case management" services under their Medicaid plan.⁴⁹ The expressed statutory purpose of targeted case management is to assist Medicaid recipients in "gaining access to needed medical, social, educational and other services." This option is unique among services afforded under the state plan, in that states are exempt from the comparability requirement to make such services available to all recipients. A state is permitted to amend its state plan to cover case management services for *specified groups of Medicaid recipients* (hence the term targeted). It may also offer these services on a less-than-statewide basis (again via state plan amendment

instead of securing a waiver).⁵⁰ (See Chapter 4 for further discussion.)

Given the expressed statutory purpose of the benefit—to assist individuals to obtain services from a wide variety of public and private programs—the scope of services a state may furnish through the targeted case management option is relatively broad. Covered activities include assistance in obtaining food stamps, energy assistance, emergency housing, or legal services. Covered activities also include service/support planning (including assessment) and monitoring delivery of the services and supports in order to ensure they are meeting a beneficiary's needs.

Financial Protections for Spouses Living in the Community

The Medicare Catastrophic Coverage Act of 1988 established special financial eligibility rules for institutionalized persons, to allow a spouse who remained in the community to retain more assets and income than had previously been allowed under Medicaid's financial eligibility rules. The figures for retainable resources are adjusted annually to reflect increases in the Consumer Price Index.⁵¹ The purpose of these rules is to prevent impoverishment of the spouse who is not institutionalized. States have the option to extend these rules to the spouses of beneficiaries receiving home and community services and also to follow the minimum maintenance allowance rules mandated for spouses of nursing home residents. (See Chapter 2 for a detailed discussion of these and other financial eligibility provisions.)

Program of All-Inclusive Care for the Elderly (PACE)

The Balanced Budget Act of 1997 (BBA) established the Program of All-inclusive Care for the Elderly (PACE) model of care as a permanent provider entity within the Medicare/Medicaid programs.⁵² This provision enables states to provide PACE services to Medicaid beneficiaries as a state option, rather than as a demonstration as was formerly the case. The number of new PACE

sites that can be established nationwide is limited to 80. The typical PACE program serves fewer than 300 individuals. PACE programs are funded by both the Medicare and Medicaid programs, and participants are generally eligible for both. PACE programs provide and manage all health, medical, and social services, and arrange other services as needed to provide preventive, rehabilitative, curative, and supportive care.

The PACE approach provides an alternative to institutional care for persons age 55 and over who require a nursing facility level of care. Services are provided in adult day health centers, homes, hospitals, and nursing homes. PACE providers receive payment only through the PACE capitation rate and are responsible for provision of all items and services covered under both Medicare and Medicaid. The individuals enrolled in PACE receive benefits solely through the PACE program.

* * *

This brief overview of Medicaid's statutory, regulatory, and policy provisions related to home and community services for people with disabilities provides a context for more detailed discussions in the chapters to come. Some of the institutional bias that remains in the program can be changed only by congressional amendment of Medicaid law (e.g., the requirement that a person must meet an institutional level-of-care standard to receive HCBS waiver services). But numerous provisions give state policymakers considerable freedom in designing their home and community service system to fit their state's particular needs. They have the option, in particular, to eliminate use of more restrictive financial criteria for HCBS waiver services than for institutional care. They also have considerable flexibility to create consumer-responsive systems that facilitate home and community living. (See Chapter 7.)

In the next several decades, as already noted, the U.S. population will age dramatically. Between 1987 and 1996, for example, the proportion of nursing home residents who were 85 and over rose from 49 to 56 percent for women, and from 29 to 33 percent for men. The severity of disability among the nursing home population has also been increasing. Almost 83 percent of nursing home residents in 1996 needed help with three or

more ADLs, for example, compared with 72 percent of residents in 1987.⁵³ Even if disability rates among older persons decline, more people will need long-term care services than at any other time in our nation's history.

Institutional care is costly. Given the projected demand for long-term care services, it is advisable for states to start planning now to create comprehensive long-term care systems that will enable people with disabilities—whatever their age or condition—to live in the community rather than rely on institutional residence and services. The Medicaid program can be the centerpiece of such a system—allowing states numerous options to provide home and community services that keep costs under control at the same time as they enable people with disabilities to retain their independence and their dignity.

Endnotes

1. The primary contributors to this chapter are Gary Smith and Janet O'Keeffe. In addition to the sources noted in the citations, a major source of information for this chapter is the *Medicaid source book: Background data and analysis (1993)*. Washington, DC: U.S. Government Printing Office.
2. The Federal government's share of medical assistance expenditures under each state's Medicaid program, known as the Federal Medical Assistance Percentage (FMAP), is determined annually by a formula that compares the state's average per capita income level with the national average. States with higher per capita incomes are reimbursed smaller shares of their costs. By law, FMAP cannot be lower than 50 percent or higher than 83 percent. In 1997, the average FMAP was 57.0 percent. States are also reimbursed for 50 percent of administrative costs. Congressional Research Service. (1993). *Medicaid source book: Background data and analysis (a 1993 update)* (p.5). Washington, DC: U.S. Government Printing Office.
3. Congressional Research Service. (1993). *Medicaid source book: Background data and analysis (a 1993 update)* (p.267). Washington, DC: U.S. Government Printing Office.
4. Data on long term services are from Burwell, B. (April 25, 2000). Memorandum: Medicaid long-term care expenditures in FY 1999. Cambridge: The MED-STAT Group.
5. Ibid.
6. Ibid.
7. Prouty, R., and Lakin, K.C. (Eds.). (May 2000). *Residential services for persons with developmental disabilities: Status and trends through 1999*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. (Study underwritten by the Administration on Developmental Disabilities and the Health Care Financing Administration).
8. Data compiled by John Drabek, Office of the Assistant Secretary for Planning and Evaluation from data collected by HCFA's Office of Financial Management.
9. Kane, R.L., Kane, R., Ladd, R.C., and Nielsen Vealie, W. (1998). Variation in state spending for long-term care: Factors associated with more balanced systems. *Journal of Health Politics, Policy and Law* 23(2): 363-390.
10. Section 1902(a)(10)(d) of the Social Security Act. Because state plan coverage of nursing facility services is mandatory for categorically eligible persons age 21 and older, home health services are mandatory for this population. If a state chooses to cover nursing facility care for younger persons, or for the medically needy, home health services become mandatory for these groups as well.
11. 42CFR 441.15 (c).
12. Medicaid Assistance Manual. 5.50.1 1977.
13. 42 CFR 440.70 (b).
14. 42 CFR 440.230(d).
15. 42 CFR 440.230(b).
16. Health Care Financing Administration. (September 4, 1998). Letter to State Medicaid Directors. (Available at www.hcfa.gov/Medicaid.)
17. *Skubel v. Fuoroli*. (No. 96-6201). United States Court of Appeals, Second Circuit. Decided May 13, 1997.
18. Social Security Amendments of 1965 (P.L. 89-97).
19. Social Security Amendments of 1967 (P.L. 90-248).
20. P.L. 90-248 effective July, 1970.
21. Act of December 14, 1971 (P.L. 92-223).
22. Social Security Amendments of 1972 (P.L. 92-603).
23. Section 1619 P.L. 96-265 of the Social Security Act .
24. Omnibus Budget Reconciliation Act of 1981 (OBRA 81, P.L. 97-35).
25. P.L. 103-66. Section 13601 (a1/5)8. Section 134 of the Tax Equity and Fiscal Responsibility Act (TEFRA) con-

tains the amendment.

26. Consolidated Omnibus Reconciliation Act of 1985. P.L. 99-272. The provision became effective April 1986.

27. Consolidated Omnibus Reconciliation Act of 1985. P.L. 99-272. The provision became effective April 1986.

28. Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360).

29. Omnibus Reconciliation Act of 1989.

30. Omnibus Reconciliation Act of 1993. Section 13601 (a)(5)8. P.L. 103-66. The changes took effect on October 1, 1994. In November 1997, HCFA issued new regulations (42 CFR 440.167) concerning optional Medicaid state plan personal care services to reflect these statutory changes.

31. P.L. 106-170.

32. Omnibus Reconciliation Act of 1989.

33. In 1987, Congress abolished the distinction between SNFs and ICFs. Nursing facilities were mandated to provide both a skilled and intermediate level of care.

34. Section 440.130(d). Other licensed practitioners of the healing arts, within the scope of their practice under state law, may also authorize services under the rehabilitation option. The statutory definition is qualified by other provisions in the law.

35. Chris Koyanagi, Policy Director, Bazelon Center for Mental Health Law. Personal communication, May 15, 2000.

36. In 1989, Congress acted to permit states that had secured HCFA approval of these coverages to continue their coverages but other states were effectively barred from adding the coverage. The Omnibus Budget Reconciliation Act of 1989 (P.L. 101-239) Section 6411(g) prohibited the Secretary of Health and Human Services from "... withholding, suspending, disallowing or denying federal financial participation ... for day habilitation and related services under paragraph (9) [clinic services] or (13) [diagnostic, screening, preventive and rehabilitative services] of Section 1905(a) of the Social Security Act on behalf of persons with mental retardation and related conditions, pursuant to a provision of its state plan as approved on or before June 30, 1989." Section 6411(g) put a moratorium on HCFA's taking actions against a state that already offered day habilitation under its state plan on or before June 30, 1989. It provided that the moratorium would only be lifted once HCFA issued final regulations that clarified the elements of day habilitation that could be offered under the state Medicaid plan as either clinic or rehabilitative services. Since passage of

OBRA-89, HCFA has not issued such regulations.

37. Smith, G., Director of Special Projects, National Association of State Directors of Developmental Disabilities Services. Personal communication, July 2000.

38. The Omnibus Budget Reconciliation Act of 1993 (Section 13601(a)(5)); Social Security Act (Section 1905 (a)(24)).

39. Individuals who reside in certain types of facilities—nursing facilities, ICFs/MR, hospitals, and institutions for mental disease (IMDs)—cannot receive personal care services through the personal care option.

40. 42 CFR 440.167.

41. Five additional states offer personal care services to children under the EPSDT mandate. LeBlanc, A.J., Tonner, M.C. and Harrington, C. (2000) *State Medicaid Programs Offering Personal Care Services*. San Francisco: University of California. The report lists 26 states with the Title XIX personal care services optional state plan benefit. Since 1998–1999, when the data were collected, New Mexico has started the benefit, bringing the state total to 27.

42. Total FY 1999 expenditures for personal care services equalled \$3,526,775. Source: Burwell, B. (April 25, 2000). Memorandum: Medicaid long-term care expenditures in FY 1999. Cambridge: The MEDSTAT Group.

43. Section 440.70(b)(3).

44. Federal regulations concerning the program are found at 42 CFR 441 Subpart G. These regulations were last modified in 1994. HCFA guidelines concerning the HCBS waiver program are contained in Sections 4440 *et seq.* of the State Medicaid Manual. These guidelines are updated periodically.

45. Data obtained from HCFA website: www.hcfa.gov/medicaid.

46. Burwell, B. (April 25, 2000). Memorandum: Medicaid long-term care expenditures in FY 1999. Cambridge: The MEDSTAT Group.

47. Figures are based on: Harrington, C., Carrillo, H., Wellin, V., and Norwood, F. (July 2000). *1915(c) Medicaid home and community-based waiver participants, services, and expenditures, 1992–1998*. Based on HCFA 372 Form Data. San Francisco CA: University of California San Francisco (UCSF). And Prouty, R. and Lakin, K.C. (eds.) (May 2000). *Residential services for persons with developmental disabilities: Status and trends through 1999*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute for Community Integration.

For both 1992 and 1998, University of Minnesota fig-

ures for individuals with developmental disabilities receiving HCBS services through the Arizona 1115 demonstration waiver were added to the UCSF figures. Where data were missing in the 1998 UCSF figures, 1997 data were used instead, except in the case of HCBS waiver programs for persons with developmental disabilities (for which University of Minnesota figures were used).

48. Average costs are calculated by dividing total expenditures by the total number of persons who participate during a year, regardless of the length of time they receive waiver services. (See endnote #47 for data source.)

49. Section 915(g) was added to the Social Security Act.

50. HCFA guidelines concerning targeted case management services are found in the State Medicaid Manual in Sections 4302 et seq.

51. P.L.100-360. (1993). *Medicaid source book: Background data and analysis (a 1993 update)* (p. 224). Washington, DC: U.S. Government Printing Office.

52. P.L. 105-33.

53. Rhoades, J.A., and Krauss, N.A. (1987, 1996). *Nursing home trends*. Rockville: Agency for Health Care Policy and Research; (1999). Medical Expenditure Panel Survey (MEPS) Chartbook No.3. AHCPR Pub. No. 99-0032.

and community based services: A final report. San Francisco: Department of Social and Behavioral Sciences, University of California. (169 pages)

The paper identifies provisions of law and regulation that contribute to institutional bias in the Medicaid program. It provides a comprehensive overview of Medicaid statutes and regulations related to the provision of long-term care services. The paper also makes policy recommendations to reduce institutional bias and thereby increase the availability of home and community-based services through the Medicaid program. *The document may be ordered for \$15.00 by e-mail at sbs@itsa.ucsf.edu or by calling (415) 476-3964.*

Harrington, C., Carrillo, H., Wellin, V., Norwood, F., and Miller, N.A. (March 2000). 1915(c) Medicaid home and community based waiver participants, services, and expenditures, 1992-1997. San Francisco: Department of Social and Behavioral Sciences, University of California. (26 pages)

This paper presents historical data on home and community based waiver participants, services, and expenditures. It describes the number and type of 1915(c) HCBS waiver programs that states operated between 1992 and 1997. It reports on trends in the number of participants and expenditures by target group and by service and discusses factors related to expenditure growth. *The document may be ordered for \$5.00 by e-mail at sbs@itsa.ucsf.edu or by calling (415) 476-3964.*

Annotated Bibliography

Feder, J. (May/June 2000). Long-term care in the United States: An overview. *Health Affairs* 19 (3): 40-56. (16 pages)

This article describes how long-term care is financed in the United States. It emphasizes the current inadequacies of the Medicare and Medicaid programs and encourages changes that will provide affordable services to those in need. The article describes reasons for beneficiary dissatisfaction with the scope, mix, quality, and financing of long-term care, which varies among states. The article also includes an overview of the population that needs long-term care, mechanisms for financing, policy implications of various proposals to improve access to long-term care, and issues policymakers should consider when seeking to improve the system.

Harrington, C., LaPlante, M., Newcomer, R.J., Bedney, B., Shostak, S., Summers, P., Weinberg, J., and Basnett, I. (January 2000). *Review of federal statutes and regulations for personal care and home*

Coleman, B., and Tucker, N. (1999). *Trends in Medicaid long-term care spending*. Washington, DC: AARP, Public Policy Institute. (6 pages)

This publication briefly discusses Medicaid expenditures for long-term care. It shows that there has been a steady increase in long-term care spending, particularly for home and community-based services (HCBS) waiver programs for people with mental retardation and other developmental disabilities. It compares allocation of Medicaid long-term care spending for HCBS waiver programs, personal care services, and home health services. A table of Medicaid home care expenditures for all states is included. *To obtain a free copy of this document, contact AARP's Public Policy Institute at (202) 434-3860 or search their website at www.research.aarp.org. Publication ID: DD38 January 1999.*

The Kaiser Commission on the Future of Medicaid. (February 1996). *Medicaid and long-term care*. Washington, DC: Author. (8 pages)

This policy brief discusses Medicaid's provision of

long-term care services. It highlights Medicaid spending on long-term care, mandated services, and eligibility requirements. Particular attention is paid to nursing home care and the laws that seek to ensure quality of care. *It may be obtained free of charge from the Kaiser Family Foundation website at www.kff.org or ordered from their publications line at (800) 656-4533.*

Burwell, B., and Crown, W. (1994). *Public financing of long-term care: Federal and state roles*. Cambridge: The MEDSTAT Group. (40 pages)

This paper provides an overview of public financing of long-term care services for elderly persons through Medicare, Medicaid, and other public programs. It presents statistics, characteristics of publicly-financed programs, and the variation in financing across the 50 states. It discusses utilization trends and the allocation of federal and state monies to pay for services such as home health and personal care. Graphs and tables enhance the presentation. The paper also discusses cost containment methods employed by funding sources, quality assurance measures, and access to care issues. It emphasizes the states' primary role in shaping the publicly financed long-term care system and the policy implications of that role. The paper provides a thorough understanding of the history of public funding for long-term care, financing options that states have employed, and considerations that must be taken into account when providing long-term care. *The paper can be obtained free of charge by writing to Pauline Chouinard at The MEDSTAT Group, 125 Cambridge Park Drive, Cambridge, MA 02140.*

Websites

The following websites provide some information about Medicaid, long-term care, or home and community services. This list is not inclusive of all the resources available on the internet, but provides a good starting point for finding information.

Federal Government Websites

Administration on Aging: www.aoa.gov

Agency for Healthcare Research and Quality: www.ahrq.gov

Assistant Secretary for Planning & Evaluation (ASPE): aspe.hhs.gov

Health Care Financing Administration (HCFA): www.hcfa.gov

HCFA's Medicaid information:

www.hcfa.gov/medicaid

Medicare/Medicaid (500 Sites): whatsonthe.net (click on *Medicare/Medicaid* under *Health*)

Murphy's Unofficial Medicaid Page: www.geocities.com/CapitolHill/5974

National Association of State Medicaid Directors: www.aphsa.org (click on *Links*)

State Government Websites

Intergovernmental Health Policy Project: www.ncsl.org

National Academy for State Health Policy (NASHP): www.nashp.org

National Association of State Mental Health Directors: www.nasmhpd.org

National Conference of State Legislatures: www.ncsl.org

State and Local Governments on the Web: www.piperinfo.com/state

Foundations

Kaiser Family Foundation: www.kff.org

The Robert Wood Johnson Foundation: www.rwjf.org

Commonwealth Fund: www.cmwf.org

Associations and Organizations

American Association of Homes & Services for the Aging: www.aahsa.org

American Association of Retired Persons (AARP): www.aarp.org

American Public Human Services Association: www.aphsa.org

Bazelon Center for Mental Health Law: www.bazelon.org

Consortium for Citizens with Disabilities: www.c-c-d.org

Independent Living Research Utilization (ILRU): www.ilru.org

Liberty Resources: www.libertyresources.org

National Senior Citizens Law Center: www.nslc.org